The Report Committee for Lauren Rochelle Sahagian
Certifies that this is the approved version of the following report:

The Dementia Family Caregiver

APPROVED BY
SUPERVISING COMMITTEE:

Supervisor:

Elizabeth D. Pena

Thomas P. Marquardt

The Dementia Family Caregiver

by

Lauren Rochelle Sahagian, B.A.

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Dedication

I would like to dedicate this report to my mom and dad, who are so loving and supportive, and who helped make coming back to school a real possibility for me. I would also like to thank my boyfriend Doug for always making me laugh, and for providing such ongoing encouragement.

Abstract

The Dementia Family Caregiver

Lauren Rochelle Sahagian, M.A.

The University of Texas at Austin, 2017

Supervisor: Elizabeth D. Pena

This report provides insight into the unique emotional and subjective experiences of the dementia family caregiver. Caring clinically for the caregiver requires an acute sensitivity to the needs of the individual. Healthcare professionals need to recognize the complex contributing factors that influence this experience. The subsequent decision for a caregiver to eventually move a family member from a home care environment into a long term living facility often is associated with an intense and conflicting emotional guilt response. Understanding the dementia caregiving experience provides an opportunity for clinicians to offer appropriate levels of support and assist the former primary caregiver in adapting to new roles and responsibilities during the transition out of homecare, recognizing family members as partners in the ongoing care process, and fostering positive family staff interactions within the facility.

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Introduction

Dementia is a brain disease characterized by a permanent and progressive decline in various domains of cognitive and intellectual function. The disruptions can significantly diminish and destroy memory, orientation, judgment, and reduce recognition of names and functions of objects and people. The disease impairs information processing, problem-solving and the sequencing of tasks. With an initially gradual onset, dementia first includes mild symptoms but becomes progressively worse. Although the disease does not directly cause death, dramatic physical decline is to be expected (Abraham, 2006). Speech-language pathologists play an important role in the screening, assessment, diagnosis, and treatment of this disease. Intervention strategies target cognition, communication, and the swallowing deficits associated with motor decline. Speech-language pathologists address the cognitive aspects of communication, including attention, memory, sequencing, problem solving, and executive functioning. They implement strategies to preserve communication abilities and cognitive functioning for as long as possible (ASHA, 2017). For clinicians working closely with dementia populations, comprehensive understanding of the caregiving experience is a necessary part of intervention strategies that also alleviate the distress of the family as much as possible.

There is importance in recognizing that while caring for the physical and emotional needs of a family member with dementia, primary caregivers are simultaneously grieving the major loss of a previously meaningful and personal relationship (Noyes et al., 2010). Caring for a relative with dementia is more demanding

than caring for family members with non-dementing illnesses due to the cognitive and behavioral deficits resulting from the ongoing progression of the disease (Connell, Janevic, & Gallant, 2001). Losing the former relationship with a family member to dementia differs from a traditional death in that the care recipient remains present physically, but is often no longer psychologically present, and has lost the ability to meaningfully interact with other people. The difficulty that caregivers confront in processing this type of loss often inhibits an open grieving process. (Noyes et al., 2010). The act of dementia caregiving often results in high levels of distress which then have an impact physically, emotionally, financially, and socially on the caregiver, as many people with dementia are cared for within the family home for prolonged periods of time (Connell et al., 2001). In an effort to more clearly understand the experience of the dementia caregiver, studies have investigated several of the key factors considered important to both positive and negative caregiver outcomes. While many of the studies are descriptive, focusing mainly on demographics (Romero-Moreno et al., 2014), there is value in recognizing that all caregivers will experience the dementia of a family member slightly differently. In the same way that dementia manifestations are variable in nature, so are the experiences of those who care for someone with this disease. Healthcare providers working clinically with those impacted directly and indirectly by this diagnosis must learn to recognize both the patterns and the differences between individuals, so that they may cater intervention strategies to most appropriately fit the needs that are present.

Dealing emotionally with the loss associated with dementia deterioration causes more strain than attending to the actual process of providing care (Noyes et al., 2010). When healthcare professionals are familiar with the disease of dementia as well as the emotional consequences of caring for someone with this disease, they can facilitate the training and education of family members in learning to recognize and accept their own limitations in such a chronically stressful situation. In providing this support, health care providers may assist the family in lessening the severity of both the physical and emotional outcomes that arise (Hepburn, Tornatore, & Ostwald, 2001).

By the year 2030, 20 percent of the United States population is expected to be at or above 65 years of age. Dementia is present in approximately 10 percent of 65 year old adults, and in 47 percent of those aged 85 and older. The number of dementia family caregivers is expected to increase with increases in the number of dementia individuals(Parks & Novielli, 2000). Although the initial responsibilities of dementia caregiving often fall to close family members, the eventual transition of a person living with this disease into a more structured long term facility is often inevitable. Upon the relocation from home environment to structured facility, professional health care staff then takes over the role of providing primary care. The comprehensive quality of this professional care depends largely on a knowledge of the dementing illness and its progression, as well as an acute sensitivity to the experience of the former primary caregiver still associated with this person despite a recent physical relocation (Abraham, 2006).

Caregiver strain has been described most commonly as a stress-process model, involving an interplay between the demands associated with caregiving and the personal resources available to the caregiver to meet these demands (Noyes et al., 2010). This model is argued, however, to be largely insufficient as an archetype for understanding such a complicated and multidimensional experience (Upton & Reed, 2006). Dementia caregiving involves grief in response to the sense of loss that is experienced over the often prolonged course of the dementing illness. Attending to a family member with dementia requires caring for the many needs of this individual, while simultaneously coping with the stress of experiencing a potentially profound interpersonal loss.

For healthcare professionals to effectively interact with and support the dementia family caregiver, recognizing and attempting to understand this form of loss is fundamental (Noyes et al., 2010). Caring for a family member with the progressive disease of dementia is complex, unpredictable, and demanding (Merrilees, 2016). Due to the intensity of the burden placed on the primary caregiver, the situation is regularly considered to be chronically stressful (Etters, Goodall, & Harrison, 2008). The degree of strain experienced by the caregiver is impacted by a variety of potentially fluctuating factors like the amount and frequency of social support and coping resources available (Connell et al., 2001).

Overview

The spouses and adult children of people with dementia most commonly assume the role of primary caregiver (Connell et al., 2001). Their perception of this experience can fluctuate and vary, but there have been several key differences distinguishing between men and women, wives and husbands, adult sons, and adult daughters. (Romero-Moreno et al., 2014). Generally speaking, the closer the relationship was between the two people prior to the onset of dementia, the higher the stress and burden experienced by this person. Along with the emotional aspects of stress, these home caregivers provide informal care with a very high frequency, rarely utilizing the services of outside professional assistance (Connell et al., 2001).

The grief response is defined as the reaction to the perception of loss, and is largely present for people with familial dementia caregiving responsibilities. The type of grief experienced by the dementia caregiver throughout the disease runs somewhat parallel to the grief that is experienced following the actual death of a family member. Called, "dual dying", the death is mourned prior to the actual physical occurrence. Following the death of the person, the caregiver must then grieve again (Sanders, Ott, Kelber, & Noonan, 2008). The magnitude of the emotional pain associated with this experience lasts for a longer period of time, but has been largely described as equal to, or more unpleasant than what is experienced in a traditional post death grief process (Noyes et al., 2010).

Caregivers often dedicate years attending to the needs of their relative while observing an unavoidable degradation in the cognition and physical health of this family

member. Due to the declining nature of the disease, caregiver health outcomes are often correspondingly negative. The perception that a caregiver has of the behavioral disturbances exhibited by the family member with dementia often have more of a negative impact on their sense of well-being than the actual severity of the cognitive decline (Connell et al., 2001). Behavioral disturbance includes a wide range of behavior, including wandering, verbal and physical aggression, and the overall agitation caused by heightened feelings of anxiety (Etters et al., 2008). During interviews, caregivers commonly report and emphasize the guilt and regret they feel about having become exasperated and short tempered with the person when they engage in these negative behaviors. They often admit to having felt extreme frustration in response to repetitive questioning and other dementia related symptoms (Sanders et al., 2008).

With less frequency, studies have emphasized the positive aspects and outcomes of caregiving, which involve a sense of feeling appreciated and needed. Increases in self-worth have been reported, as well as a special strengthening of the relationship between the care giver and the care recipient(Losada, Pillemer, Márquez-González, Romero-Moreno, & Gallego-Alberto, 2016). Family members describe their focus shifting to the remaining abilities of their family member despite a global decline. They may report having found a higher purpose in life, as well as a sense of gratitude for the time that they spend together with this person. There is an importance, however, in viewing this experience without a polarized positive or negative emphasis(Losada et al., 2016).

Ambivalence is explained as the presence of two simultaneously opposing ideas, attitudes, or emotions, often contributing to feelings of uncertainty caused by complex psychological conflict. In a study that measured the psychometric properties of the feelings of caregivers, 401 face to face interviews were conducted using the Caregiving Ambivalence Scale (CAS), which measured the presence of ambivalence, depression, anxiety, and stress. A significant positive correlation was found between depression and anxiety symptoms and the frequency of, and caregiver reaction to, the disruptive behaviors demonstrated by the person with dementia. The inconsistent and ambivalent nature of the emotions indicated by caregivers on the CAS scale was attributed to the continually fluctuating state of response involved in this type of care. At some times, a given situation elicited positive emotions in these participants, while at others, feelings had negative connotations. The emotional fluctuations experienced by the dementia caregiver throughout the disease process led to very changeable relationships with the care recipient. This somewhat unpredictable emotional variability and fluctuation is difficult for the caregiver to handle. Without an awareness and acceptance of this ambivalence as an expected part of the dementia caregiving process, feelings of stress, guilt, and anxiousness become heightened. When a caregiver denies the ambivalence that they are likely to be experiencing, there is an increased likelihood for the use of maladaptive coping strategies, including the suppression of unpleasant emotions. Suppressing “negative” emotions, rather than an honest acknowledgement of them, has the potential to cyclically increase the frequency and intensity of the emotions that are essentially ineffectively being minimized. A majority of the undesirable emotions

reported by caregivers during this study were found to stem from the change in a previously meaningful relationship with the care recipient, and also in the denial of their own caregiver needs (Losada et al., 2016). A change in the relationship dynamic is inevitable. It is important for caregivers to recognize that establishing and fulfilling their own needs will not take away from the care recipient, but instead increase their own sense of wellbeing as they are faced with the challenge of finding new meaning within the relationship.

Ultimately, both positive and negative feelings are simultaneously associated with dementia caregiving. While the negative outcomes may be more intuitive, as well as more frequently studied, positive outcomes exist. As the disease becomes more advanced, the stress experienced by the primary caregiver is likely to become more prominent, and can begin to feel unmanageable. The quality of communication between the caregiver and the care recipient diminishes, and they become unable to participate in meaningful activities together. Consequently, caregivers occasionally can find themselves hoping that somehow the situation will eventually return to normal (Losada et al., 2016).

Contributing Variables in Caregiver Outcomes

Research relating to dementia care has focused on key caregiver characteristics that contribute to outcomes in dementia family care. The three most commonly studied elements are the gender of the caregiver, and whether or not they are a spouse or the adult child of the care recipient. What remains somewhat unclear is exactly how these characteristics intersect with one another (Chappell, Dujela, & Smith, 2015). Healthcare providers must know how these key characteristics contribute to the caregiver experience, while understanding and expecting that individuals are likely to differ with a complexity that is largely unknown. There are four key factors that have been investigated as key to foundational awareness.

Family and Social Interactions

Although family strain is commonly associated with dementia caregiving, this process has received relatively little attention within the scientific community (Merrilees, 2016). Conflicts generally result directly from the existence of the dementia, but can also be related to previous tensions which become worsened as the demands placed on the primary caregiver increase. The primary caregiver often senses a diminished level of support from other family members, and this creates conflict (Etters et al., 2008). Family members report difficulty in reaching a consensus relating to the presence and severity of the symptoms of cognitive decline, and also in making a mutually shared decisions regarding care (Merrilees, 2016). A strained family environment has been found to be a predictor of caregiver depression, and as the cognitive abilities of the person with dementia decline, caregivers commonly perceive their families as less flexible and more disagreeable(Etters et al., 2008). Sibling conflict also is common between caregiver and non-caregiving brothers and sisters, contributing to increases in stress and a decline of familial well-being (Connell et al., 2001).

The burden experienced by the primary caregiver lessens when encouragement and appreciation of care are expressed by other members of the family (Etters et al., 2008). In a study involving 46 qualitative research interviews of dementia caregivers, the only support that caregivers said they would have appreciated was an occasional visit from an outside sitting service or from a relative or friend showing sincere interest in spending one on one time with the person being cared for. However, this relief was rarely, if ever, offered (Upton & Reed, 2006). Determining modifiable sources of

conflict within a family dynamic is a useful way of helping to alleviate caregiver strain. Intervention strategies should consider the contributions of all members of the family. In the same way that ambivalent emotions arise within the relationship between the caregiver and the person with dementia, similar emotional fluctuations can occur between the caregiver and other family members, particularly when a caregiver is unable to efficiently problem solve or assert themselves (Losada et al., 2016). Commonly, the support-caregiver coping relationship is characterized by the psycho-physical separation of friends and family. This is either done through a physical or an emotional distancing from the dementia. Spouses who live in the same home as their care recipient face more of this degradation as a result of dramatically limited social contact with others, but are in some cases then thought to be protected more from vulnerability in that they can spend less time and energy balancing two lives with strained resources and time (Upton & Reed, 2006).

Social support lessens caregiver stress, providing a level of emotional assistance that is tangible to the caregiver. Lower levels of social support are associated with poorer physical health, as well as increased burden and feelings of depression. A positive perception of the social support network has more weight than the amount social assistance actually received. The reality, however, is that the roles and responsibilities of the dementia caregiver often greatly limit the opportunity for social contact. As the severity of the symptoms of the disease increase, the amount and quality of social support received tends to fall correspondingly (Connell et al., 2001).

Gender

Gender plays a role on the impact that caregiving has on the health of the individual. Female caregivers present with higher levels of depression, anxiety, and other psychiatric symptoms than their male counterparts (Connell et al., 2001). Female caregivers also are at the highest risk for experiencing caregiver burden (Etters et al., 2008). One possible factor in explaining this phenomenon is that males and females have been found to plan and complete tasks in different ways. Women caregivers have a tendency to take on a multitude of tasks simultaneously, while men are commonly observed to perform their duties in a more linear fashion. Men plan and prioritize a smaller number of tasks, which later provides them with more time for pleasurable activities and relaxation (Connell et al., 2001). Women also generally take on far more responsibilities than their male counterparts. The type and frequency of the tasks performed by males and females differs as well. Women spend more time performing duties that require hands on assistance like clothing, toileting and bathing. They also perform a larger number of household chores like cleaning and preparing food. Women are more likely to perform shopping duties and to transport the care recipient to the various activities of daily life (Connell et al., 2001). Female caregivers also have reported performing care in a more emotionally driven manner than men, who are more likely to remain logical and results oriented. The proposed ideal method for caring combines both of these two approaches (Connell et al., 2001). Men demonstrate lower levels of burden as compared to their female counterparts, but there is not clarification on whether this is as a result of men being somehow more immune to this emotion, are

hesitant to admit to it, or because they administer care in a way that is different from that of women (Merrilees, 2016). There is comparably less available data regarding the experience of the male caregiver exclusively. A frequent challenge reported by men is that they are less comfortable taking advantage of formal community resources like emotional support groups because they are generally perceived as being geared more towards the female caregiver (Connell et al., 2001).

Spousal Caregivers

Grief escalates over the course of dementia for spousal caregivers. Sadness is felt in the early stages, with spouses anticipating a worsening of their own grief symptoms as the disease inevitably advances. In the middle stages of the disease process, spouses are often found to externalize their grief. At this point they become overwhelmed with sadness regarding what the disease has stolen away from the person that they love, rather than what they have lost themselves. In the very last stages of the disease the sadness is most internalized. The caregiver reflects back upon how dementia has changed life for them over the years. The emotional response largely involves thoughts of what the future will bring for them now that they are on their own (Sanders et al., 2008).

Spouses often report higher levels of depression and lower levels of general satisfaction with their lives than other types of dementia caregivers, and they participate less frequently in social activities (Connell et al., 2001). The disease creates an environment that is isolating not just in a broad social sense, but also on an interpersonal and intimate level with the other person. The type, stage, and length of the presence of the dementia all impact these levels of isolation(Upton & Reed, 2006). The heightened strain reported by spouses is likely to result from these caregivers providing the most comprehensive care, for the longest periods of time, for the most hours per day, for the individuals with the highest levels of physical and cognitive impairment. They also may be dealing with their own age related health challenges, such as chronic illness and a decrease in physical and cognitive resilience (Connell et al., 2001). They

feel as if they must place their needs behind those of the spouse, and their lifestyle must accommodate the person with dementia. The spouse often requires constant monitoring, and as a result, the sleep of the caregiver is also impacted. In a study of 92 family caregivers, one third of them also reported having experienced physical violence at some time. Married couples often live alone, so there is importance in considering the existence of situations potentially involving both physical and verbal abuse. A caregiver who is abused may be living in fear, or attempting to protect their spouse. A correlation has also been found between caregivers who have been exposed to abuse who then become violent in return (Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014).

Spousal caregivers are faced with loneliness. They are dealing with the loss of a partner and also the dissolution of a marriage (Merrilees, 2016). Social connectedness and the previous roles assumed within the relationship are forced to shift. Activities once shared as a couple become more limited as the symptoms of dementia intensify. Husbands in particular demonstrate increased levels of social isolation, largely due to the fact that their wives were often previously responsible for forming and maintaining social connections with others (Connell et al., 2001). Spouses typically considered their relationship with the partner prior to the onset of dementia to have been their primary social connection and support. Cognitive impairment leaves the caregiver feeling socially isolated and stigmatized. This isolation is largely responsible for their heightened levels of grief (Sanders et al., 2008). No longer belonging to a previously established social network has a somewhat gradual onset, similar to the progression of the dementia symptoms. In a series of interviews conducted with caregivers, spouses

report initially making an effort to keep up with their social community. This was accomplished by leaving the person with dementia alone at home for limited periods of time, or by bringing the spouse along. Despite these strategies, the focus was always on the person with dementia. As the symptoms of dementia became more advanced, caregivers reported feeling trapped at home, unable to manage the behavior of the spouse. Friends would often stop extending social invitations when they perceived that there was shame regarding the behavior of the partner. When spouses feel ashamed of their partner, they suppress the emotion in an attempt to avoid the guilt associated with the shame. Behavior management becomes progressively more problematic in novel environments, and caregivers will avoid social situations out of convenience (Høgsnes et al., 2014).

Caregivers can interpret the attempted assistance of friends and family as creating more unwanted stress. They do not receive the help that is necessary to deal with the person from anyone else. The caregiver spouse takes on the responsibility of caring alone, and often accepts that the experience will not be handed off to another person. For the spousal caregivers living in fear of the eventual institutionalization of their partner, there is a hope that they will outlive the spouse. For those who did not have a firm opposition to the idea of long term care, this is considered an absolute last resort (Upton & Reed, 2006).

The most beneficial thing that a non-primary caregiving family member can do to assist in alleviating the stress of a spouse is to let the caregiver know that they have not been forgotten. The spousal caregiver is aware of the responsibilities that they have

taken on, and also know that the ability for their spouse to remain living at home relies solely on them. In a 46 person phenomenological study conducted in an effort to understand the influence of social support on caregiver coping, caregivers reported that it was common for family and friends to only offer help that required no hands on assistance. These same family members who avoided helping with the activities of daily living were generally also those who insisted that professional help was sought out instead (Upton & Reed, 2006).

Adult Children

The grief of adult children caregivers differs from that of the spouse. In the early stages of the disease, the grief manifests as a denial of the dementia. Although most are daughters, all adult children generally show greater levels of guilt than other types of caregivers. Rumination will occur over events from the past involving the parent, and their reaction to the diagnosis is generally handled with great difficulty (Sanders et al., 2008). Daily life often is more impacted for adult children caregivers than it is for spousal ones, particularly daughters, as they may be working and simultaneously caring for other members of the family. This contributes to a reported increase in their need for greater social support. Adult child caregivers report lower levels of caregiver esteem, and their anxieties are frequently magnified as they are faced with the realization that they may also eventually become inflicted with dementia (Hogsnes, Norbergh, Danielson, & Melin-Johansson, 2016). A study of siblings who were caring for parents also noted that tensions between siblings will increase when there is favoritism detected or perceived (Merrilees, 2016). Siblings will worry about themselves, and also one another eventually presenting with the disease.

Overview of Contributing Factors

A reported sense of powerlessness is experienced in having to take care of someone who does not understand that they need help. Adult children commonly encounter periods when they are faced with more than they can handle, and this brings up feelings of anxiety and inadequacy. Their life becomes less flexible as the parent demonstrates progressively more advanced signs of cognitive decline. In a series of face to face interviews conducted with adult child caregivers ranging in age 48 to 65 years old, Hogsnes, Norbergh, Danielson, and Melin-Johansson recalled a caregiver story involving a parent who would sometimes call the child more than 150 times in one day, with only one or two minutes in between calls. When the child tried to discuss the calls, the mother became upset and started to cry. The mother was unaware that she had been engaging in any inappropriate behavior, and did not understand why the child did not want to talk to her anymore. When a parent is no longer able to hold a cohesive conversation with the adult child, there is a sense of great loss. Adult children are faced with the sadness that their parent is slipping away from them as the personality makes a complete metamorphosis. They feel as if they do not know who the parent has become despite physical sameness. Those interviewed for this study reported feeling that they were solely responsible for the well-being of their parent as there was no one else who would do it if they did not. In some cases, the parent with dementia would explain to the child that they would not be open to accepting help from anyone other than them. In the fear of having to deal with the backlash related to getting outside assistance, the child felt pressured to take on all responsibility alone. In line with the fluctuating elements of

ambivalence, adult child caregivers mentioned caring for their parent as a simultaneously positive experience, giving them a chance to bond more closely, and spend more time together. There was a pleasant sense of satisfaction associated with the notion of mutual appreciation. Positive thoughts lessened the impact of distress and anxiety experienced (Hogsnes et al., 2016).

Relocation

As the burden associated with dementia caregiving increases, families are eventually faced with the difficult decision of whether to place their family member into a long term care facility. Towards the end of the home care process, several crises often occur which make the decision to continue care at home unrealistic (Sanders et al., 2008). Although education, support, and respite care can help to prolong home health care, there is an inevitable need for more help eventually (Etters et al., 2008).

There is often a great level of guilt associated with the relinquishment of a family member. Even when this move may have been strongly encouraged for long periods of time by others, including medical professionals, the caregiver will feel guilt associated with giving up full responsibility. Caregivers commonly feel as if they have broken a promise to the care recipient. Discomfort and self-doubt is further intensified if they also feel unsatisfied with their perception of the quality of care within the new facility, or do not feel welcome there (Sanders et al., 2008).

Despite an alleviation of the strain and conflict that was likely experienced at the end stages of homecare, the concern of the caregiver often continues following long term placement (Graneheim, Johansson, & Lindgren, 2014). The caregiver finds relinquishing care difficult, and will make efforts to remain involved (Alice Lau, Lotus Shyu, Lin, & Yang, 2008). However, the responsibilities that were once taken on by the family caregiver are now left to the oversight of unfamiliar professional (Abraham, 2006). Families often are not prepared to deal with the shift from direct caregiving into a more passive role, and nursing home staff frequently provide little or no guidance to

the families who require assistance and continued involvement as they make this transition (Maas et al., 2004). The family member may feel as if their presence and help are not welcomed by the medical staff. They also no longer feel as if they are the most important person in the life of their family member, and so they begin to grieve again (Graneheim et al., 2014). Continued contributions of family members in assisting with dementia in the nursing home care make an impact on quality of life for the person with dementia. If a caregiver perceives their role following a long term care placement to be welcomed, respected, and confirmed by the healthcare professionals, and if they are kept involved and informed, they experience the transition with less discomfort, and are more likely to continue an ongoing and important role in providing this comprehensive quality of care (Moyle et al., 2014).

Spouses after Relocation

Relocating a partner to a nursing home left spousal caregivers feeling the guilt of failure. This was exacerbated by the fact that the person was not cognitively capable of meaningfully contributing to the decision. At the time of the relocation, caregivers have typically been under high strain for a prolonged period of time. Despite the discomfort, they report feeling as if they could have, and should have done more. The physical relocation of their spouse promotes a sense of freedom and lessened social isolation, but also is associated with the guilt of feeling as if they gave up on the person when they should have provided more care. Their new sense of freedom is simultaneously plagued with a feeling of powerlessness. Prior to relocation the caregiver felt loneliness as a result of diminished social contact, but after the spouse is no longer living at home this loneliness becomes more existential in nature. The loneliness is related to the sense that as humans in general we are ultimately alone (Høgsnes et al., 2014).

Spouses reported an importance in trying to accept their new life without living physically with their spouse. Some felt comforted by keeping the home or the garden intact as a representation of their previous life together with this person. One male spouse described mentally separating life into memories from before and after the disease, because focusing on the positive memories helped him to move forward with the rest of his life (Høgsnes et al., 2014).

Adult Children after Relocation

Relocating a parent to a nursing home allowed adult children to feel as if they could recover their sense of independence and freedom. They generally felt as if the needs of the parent were being met in an environment that was safe and satisfactory. Following the relocation, they reported having the regained ability to take proper care of themselves and their families, but commonly were left with a sense of emptiness. In a series of caregiver interviews conducted by Hogsnes, Norbergh, Danielson and Melin-Johansson, an adult child caregiver reported that they often felt as if they had forgotten something. Having previously dealt with incessant and stress inducing telephone calls from their mother, the caregiver now no longer received any calls. Despite the sense of freedom reported by these caregivers, a sense of unease is present simultaneously. Adult children know that the parent would often have considered living in a nursing home as the worst possible outcome, so many children feel a sense of guilt. They will visit frequently, but secretly wonder if this is because they feel a moral responsibility to do so. To combat the sadness at having essentially lost the parent, they will make an effort to keep memories of the healthy parent (Hogsnes et al., 2016).

Relationships with Death

Caregivers report a change in their perception of death. The progression of dementia elicits thoughts of mortality, and the caregiver commonly feels as if the person has already gone. Caregivers feel uncomfortable when the person tells stories about having recently spent time with people who are already deceased, and sometimes stories about the dead are more common than any other kind (Hogsnes et al., 2016). Living within such close physical and emotional proximity to death has an existential impact upon the caregiver. The grieving process begins well before a physical death, as the personality is gone before the body. The person with dementia may be perceived as existing in between life and death, with the thoughts of a true death often easier to handle (Høgsnes et al., 2014).

Conclusions

The medical advancements of the second half of the twentieth century have contributed to such a noticeable rise in the prevalence of dementia. Longer life expectancies are associated with such an increase, as dementia is typically a disease of later life (Abraham, 2006). For geriatric healthcare providers, there is great value in understanding the complex process of family dementia care (Noyes et al., 2010). No form of caregiving is capable of preventing the ultimate outcome of this disease, but continued family involvement following institutionalization can have a positive impact on the quality of life for those involved. Although the process of dementia starts, and eventually will end for the person who is diagnosed with the disease, bridging the gap between familial and professional caregivers may foster a sense of unity and alleviate some suffering. Possibly the most effective way to ameliorate caregiver strain is to embrace and encourage the notion that living in close proximity with dementia is a largely isolating and unpleasant experience. Understanding the wide range of emotional responses associated with this form of caregiving may help to normalize the experience. Embracing the idea that pain is an inherent part of this process may help those grieving to accept the loss with less resistance (Noyes et al., 2010).

There is not one simplistic or consistently efficient strategy for easing the stress of caregivers, and this presents a challenge for the professionals working in an effort to minimize harm and alleviate unnecessary suffering (Connell et al., 2001). Clinical professionals who are willing to form meaningful partnerships with caregivers provide a safe and supportive opportunity for these family members to modify their role while

continuing to participate in active care management. An integrative collaborative care model enables the caregiver to advocate and negotiate on behalf of their family member while simultaneously learning to adjust to changed relationships and responsibilities. Compassionate support from clinicians may encourage family members in redeveloping a positive outlook for the future (Kellett, 2007). Providing customized education about the stages of the dementia disease process will allow for a modification of expectations, permitting caregivers to recognize and set realistic personal limitations (Hepburn et al., 2001). A positive and non-threatening relationship between families and healthcare staff encourages more detailed personal disclosure and patient history information, assisting in the development of more symbiotic partnerships in long term care (Alice Lau et al., 2008). Open communication encourages primary caregivers to talk about their feelings and experiences, which may also allow caregivers to relinquish some personal feelings of guilt and shame (Høgsnes et al., 2014). The involvement of family caregivers in staff meetings and treatment plans also reinforces this sense of collaboration and teamwork with a whole person-centered approach to intervention (Graneheim et al., 2014).

Continued, more longitudinal research into the experience of the dementia family caregiver will provide clinicians with more tangible intervention strategies to help alleviate some of the heightened burden associated with providing care. Research data must be translated into less restrictive and implementable clinical care practices. The dementia caregiving experience is highly variable, requiring a flexible and forgiving framework which promotes adaptive coping over potentially long periods of time and decline (Connell et al., 2001). Family caregivers and clinicians must develop

agreeable roles and work together as they continue to share the caregiving responsibility (Maas et al., 2004).

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